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PROGRAM REVIEW AND INVESTIGATIONS COMMITTEE

**Statement of Brian S. Becker**  
**State Representative for the 19<sup>th</sup> Assembly District**  
**before the**  
**Public Health Committee of the Connecticut General Assembly**  
**March 16, 2012**  
**in support of**  
**Raised SB 369**  
**An Act Concerning Authorization for the Use of Feeding Tubes and**  
**Antiepileptic Medications in School Settings**

Chairman Gerratana, Chairman Ritter, Ranking Member Welch, Ranking Member Perillo, and the other distinguished members of the Public Health Committee, thank you for raising and taking the time to hear testimony on SB 369, An Act Concerning Authorization for the Use of Feeding Tubes and Antiepileptic Medications in School Settings.

I met Alyssa for the first time last year when I read Dr. Seuss books to her and her kindergarten classmates at The Solomon Schecter Day School. Alyssa is an active, bright and engaging six-year old little girl. She is an integral part of her class and fits in very well with the other children.

As you heard in testimony from Alyssa's parents and others during last year's public hearing, Alyssa also suffers from Glycogen Storage Disease ("GSD") and is the only person in the world who has this disease and is also cornstarch intolerant.<sup>1</sup> As a result, Alyssa must be fed approximately every 90 minutes (the exact intervals between feedings are determined by her caregiver based on Alyssa's activity and stress levels). As you also may recall from last year's testimony, Sarah Sullivan, a non-licensed individual, has been successfully tube feeding Alyssa pursuant to a

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<sup>1</sup> Cornstarch is often used to keep GSD patient's glucose level in the normal range.

physician's orders since 2008. You will hear from Alyssa's parents and Sarah Sullivan, again, later today in addition to others who support this bill.

I know that this committee also received testimony from two nurses who oppose allowing unlicensed individuals to administer tube feeding to children in schools. As support for their position, they cite the current statute and concerns about compromising the safety of children.

As to the statutory argument, while I agree that under current statute there may be a lack of clear authority permitting an unlicensed individual from performing tube feeding in a school, that is the precise issue the bill before you seeks to address. The current statute allows trained, unlicensed individuals to perform tube feeding in day programs or respite centers, Department of Developmental Services ("DDS") residential facilities, and facilities that receive support from DDS. The bill before you seeks only an extremely narrow extension of the current law to allow trained, unlicensed individuals to perform like services for "persons who have Glycogen Storage Disease and a feeding disorder and attend public or nonpublic schools."

As for the concerns about compromising the safety of children, I think the testimony you have heard in the past as well as the testimony you will hear today, will provide you with enough evidence to conclude that, if anything, having a trained person who is intimately familiar with the individual idiosyncrasies of a child suffering from GSD and who can stay in the classroom to observe the child for long periods of time will provide the child with the protection she or he needs. The additional attention a dedicated caregiver can provide may result in even better care than can be provided by a licensed person who is unable to spend as much time with the child due to the pressing needs of multiple children (such as a busy school nurse).

Borrowing from other areas of the law involving children's issues, the most important question each member of this committee should consider when deciding whether to pass this legislation is: "What is in the best interests of the child?" I hope you will conclude, as I have, that the best interests of Alyssa would be to allow her to maintain the continuity of care that she has had throughout her life.

Please help Alyssa. Please support this bill. Thank you.